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Advocates for disabled worry about new state rules

Posted By Alicia Freese On July 18, 2013 @ 7:41 pm In Top Story List | 5 Comments

BERLIN — People with developmental disabilities, their parents and advocates urged the Department of Aging and Independent Living (DAIL) Thursday not to exclude them from decisions about their care.

The department wants to make changes to the way it determines who is eligible for care and what services it offers. Roughly 40 people attended and about 20 people weighed in on the proposed changes at a public hearing in Berlin.

To an untrained eye, the changes DAIL is proposing to its System of Care Plan look like nothing more than minor wording adjustments. But advocates steeped in the legalese of disability rights say the rules would completely alter the power dynamic between the state and some of its most vulnerable clients.

One of the changes applies to people already in a program who request additional care. It allows DAIL to "consider the person's whole budget for consideration of the best way to meet the person's new needs."



[1]

Barbara Prine, an attorney with Vermont Legal Aid.

Advocates say that's essentially a way for the department to circumvent the normal decision-making procedure, cutting local providers and clients out of loop. Barbara Prine, an attorney with Vermont Legal Aid, said the message that sends to people with developmental disabilities is, "if you think you need more, we are going to take the decision out of your hands."

DAIL also wants to add language that would allow it, "in the event of fiscal pressures," to "institute changes to service options and how services are provided in order to be more economical while maintaining flexibility and choice, and/or take any other action reasonably calculated to manage such pressure."

Advocates' interpretation of that mouthful? If the department is running low on money, it can decide how to trim back costs. Right now DAIL has to wait 60 days

before making any changes, giving clients, providers, advocates and the governor-appointed committee that advises DAIL on developmental services programs, time to comment.

That's especially troubling, according to Karen Schwartz, director of the Vermont Developmental Disabilities Council, because DAIL is already exempt from the normal approval process for state agencies that want to change their funding priorities. That process, governed by Vermont's Administrative Procedures Act, requires agencies to obtain public and legislative input before going ahead with a change.

"This would take out the minimal public input that exists," Prine said, and leave the decision completely up to "departmental discretion."

Nicole LeBlanc, a member of Green Mountain Self-Advocates, said the wording change "leaves the barn door wide open" for the department to cut back on services.

"It's kind of scary as a parent to think changes could be made without us being notified or involved," Bonnie Jamieson said.

Ellen Riley, whose 16-year-old son has Down Syndrome and will soon be getting care from the Developmental Services division, asked the deputy commissioner of DAIL, Camille George, sitting across from her, to answer a simple question: "Why are you doing this?"

A third proposal would let DAIL shave off \$50,000 from the maximum budget that can be approved for individuals, bringing it down to \$250,000, and would require reassessments of the budgets every three months.

Budgets tend to creep up to the hundreds-of-thousands realm when providers decide clients need intensive supervision to prevent them from harming themselves or others. There are about 20 people with budgets in this range. Agency of Human Services Secretary Doug Racine has tried to cut costs for <u>released offenders</u> ^[2] who fit the same bill.

Advocates acknowledged that the costs are staggering. But Marie Zura, director of developmental services for the Howard Center, which serves some of those people, said she wouldn't be able to deliver the same services under the new budgetary confines. The cap creates a dilemma, Zura said, "Do we disrupt people we've stabilized ... just because we decided to institute an arbitrary cap?"

Some of the concern among advocates can be traced to the most recent legislative session, in which DAIL Commissioner Susan Wehry told lawmakers the department would need to <u>cut</u> \$2.5 million [3] in order to stay within its budget.

The Legislature said DAIL had to work with advocates when choosing where to trim back, and it couldn't take any action on this front until Sept. 1, 2013. Schwartz said the changes DAIL has put on the table would enable it to make those reductions unencumbered by objections from advocates.

One after another, the people at Thursday's hearings told DAIL officials that it shouldn't take decisions out of the hands of the people "in the trenches" — clients and their caregivers.

5 Comments To "Advocates for disabled worry about new state rules"

#1 Comment By Cyn Hennard On July 20, 2013 @ 7:18 pm

It seems to me that the best way to cut costs is to start with the payments to the provider. If we are ever going to costs under control, you need to look at that end rather than the client receiver's end.

#2 Comment By Bethany Knight On July 21, 2013 @ 7:56 am

Oh, in a perfect world, none of us would hear the words, "in the event of fiscal pressures." But ours is the real, not the ideal world. We all are asked to make adjustments, and have been. Those of us who have come to depend on government must begin to develop additional community supports, to prepare for the inevitable day the spigot goes dry. Taxes are finite... human needs are not.

#3 Comment By rosemarie jackowski On July 21, 2013 @ 10:02 am

First, a "Thank You" to Attorney Prine.

This is serious news after more than 300 reported cases of abuse of the elderly/disabled were ignored by the State.... no wonder 'they' pushed for Assisted Suicide.

And don't forget about the murders in nursing homes in the southern part of the State. Two were reported. No one knows how many go unreported.

#4 Comment By Barbara Blanchette On July 21, 2013 @ 11:34 am

I am not sure of whom Cyn Heennard is referring to as the "provider", however I am a Provider and have been for almost 23 years. We are diffinently not the ones that deserve a CUT.

We work 24/7 Most of us are their strongest of advocates

#5 Comment By Franklin Lambert On July 21, 2013 @ 11:39 am

Community support IS local government's use of tax dollars to assist members of the community. Relying on some "mythical" outside help from non-governmental sources is not the answer, because the help is irregular from these sources as history shows.

The tax revenue is abundant for the death and destruction industry, erroneously called the "Defense Budget", which should be reduced by 75% and those tax dollars redirected to help fund the truly needy which is the topic of this article.

And as far as the "spigot going dry", it will run freely if the super-rich and large corporations pay their fair share of taxes, rather than tax avoidance which has been ruinous to this country, and for that matter, to any nation following the same money-hoarding and tax avoidance philosophy.

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- [2] released offenders: http://vtdigger.org/2013/05/23/services-cut-for-inmates-with-serious-functional-impairments/
- [3] cut \$2.5 million: http://vtdigger.org/2013/04/09/budget-battle-unfolds-in-dails-developmental-services-division/

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